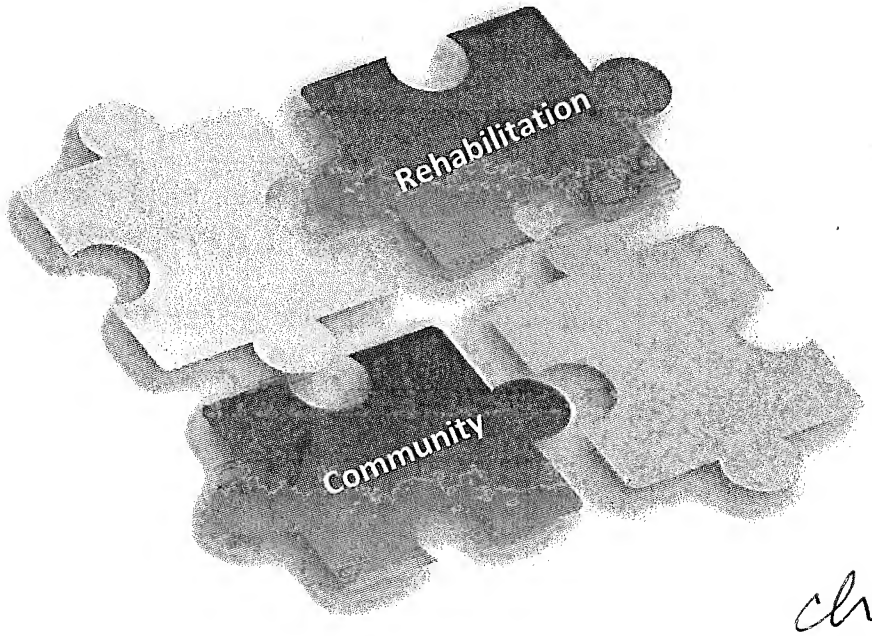
Integrated Community Based Rehabilitation Services for People with Acquired Brain Injury Champlain 2016: A Health Priority



change.
Age 35 vs 45 yrs

ABI Working Group

The Ottawa Hospital Rehabilitation Centre

May 24, 2016

The Ottawa Hospital | L'Hôpital d'Ottawa

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Acknowledgements

This report represents the contribution of many individuals and organizations who contributed their time and expertise with the goal of enhancing community based rehabilitation services for people with an acquired brain injury and their family members in Champlain. Our deepest appreciation is extended to:

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I. Executive Summary

Acquired Brain Injury (ABI)[1] is a leading cause of death and disability for individuals in Canada under age 45.[2] Brain injury can result from a traumatic external force to the head or by non traumatic means such as illness.

Recent data suggests that the demand for community based rehabilitation services for individuals with ABI grows annually.[3] Current resources cannot meet demand resulting in long wait lists, and individuals residing in settings that are not best-suited to their needs for care and support.

At present, the Champlain LHIN has 15 transitional and permanent residential spaces for individuals with ABI who require support. The average wait time for a permanent residential space is 12-15[4] years, with 45 people on a wait list. People with ABI and their caregivers in Champlain are asking for improved housing options and coordinated care with trained staff who can support the individual's ongoing health and wellbeing.[5]

Issue

How to improve community based living and rehabilitation services including housing and supported independent living options for individuals with ABI in Champlain. This can be achieved through leveraging existing funded resources to build capacity and through investment in a model to create specialized ABI services in a community-based supported housing environment for individuals with severe behaviour dysfunction requiring 24/7 supervision currently residing in Champlain ALC beds.

System Improvement Recommendations

It is recommended that:

1. The Champlain LHIN endorse a framework for an integrated Community Based Rehabilitation model for individuals with ABI that supports the LHINs priorities.
    a. Integration: A single ABI service provider or lead agency with effective system navigation will enhance integration within ABI services and across sectors such as mental health, addiction, community and social services, and housing.
    b. Sustainability: A model that is built on clinical direction and leadership facilitates and ensures transition of clients to the appropriate level of support and service and thereby increases system capacity and sustainability.

[1] Toronto ABI Network refers to damage to the brain, which may be caused: traumatically, for example, from an external force such as a collision, fall, or assault, through a medical problem or disease process which causes damage to the brain, e.g., anoxia, non-progressive tumour, infection, aneurysm, etc.
[2] Brain Injury Association of Waterloo Wellington (BIAWW), http://www.biaww.com/stats.html
[3] Parsons, D and Shah N. 2014 pg 19-20, In Champlain, there are over 1000 new cases annually requiring acute care. Of those, over 100 patients/year required inpatient rehab services."
[4] Parsons, D and Shah N. 2014
[5] Feedback project focus groups (see Appendix 4)

c. Access: Transitional care fundamental to this model will provide greater access to services across the continuum. In addition, the elements of case management and systems navigation also lend themselves to enhancing access and reducing waitlists. Case management is required at a clinical level to support client transition through and across different services and sectors. Broader system level opportunities to build capacity and efficiencies across sectors should be the primary function of the ABI System Navigator.

Current system "is Full".

2. The Champlain LHIN consider integration of funded community based ABI services[6] to ensure the clinical direction of a Neuropsychologist and administrative direction of a single program governance structure, and with strong clinical linkage to both primary care and The Ottawa Hospital Acquired Brain Injury Services.

Do other hosp's in Champlain offer ABI services?

3. The Champlain LHIN consider an advocacy strategy with the Ministry of Health and Long Term Care and the Ministry of Community and Social Services for the investment of 5 million dollars in capital and operational funding to:

   a. Create a specialized ABI community-based supported housing facility for capacity of 6 residents, as part of Champlain's regional Community Based ABI services, for individuals with severe behaviour dysfunction requiring 24/7 supervision and currently residing in Champlain ALC beds.[7]

4. The Champlain LHIN consider an increase in one time funding to the Robin Easey Centre of $80,000[8] to identify and create transitional plans for current community residential clients and invest in clinical support to assist with transition of 2-3 residential clients to appropriate resource intensive level of care.

- Derek (VC) (Jan 17) - 1 Pathways

- Why REC? (VC could be done at any prog & its prog for free) ie for free)

5. The Champlain LHIN consider additional annualized operating fund increase to the current residential provider[9] of $172,000[10] to accommodate the transition of 2 individuals requiring 24 hour support currently residing in Champlain ALC beds. - what about current waitlist (not) necessarily in ALC Beds?)

6. The plan for integration of services includes reallocation of the current funding and accountability for the ABI System Navigator role to the Robin Easey Centre with a mandate to facilitate cross sector service integration in housing and supported living.

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[6] Robin Easey Centre of The Ottawa Hospital, Vista Centre Brain Injury Services, Pathway to Independence Services, City of Ottawa Day Program

[7] Estimated annual hospital cost for 3 ALC patients - $1.02 million

[8] Neuropsychology consultation and Life Skills counsellor

[9] Vista Centre Brain Injury Services or Pathways to Independence - Pathways not a funded HSP in Champlain

[10] Cost Estimate - 2.5 behavioural support workers @ $148,000, annualized over 10 years, $172,000 @ inflation rate of 1.69%

II. Introduction/Background

i. Scope of Project

Funding was provided to The Ottawa Hospital Acquired Brain Injury Program in December 2015 to propose a model for integrated and enhanced community rehabilitation services for individuals with Acquired Brain Injury. Objectives of the project were to:

1. Propose a model of community based rehabilitation services that is evidence based, and includes accountability structures that would support improvements to evidence based service provision, waitlist management and efficient use of existing resources and would build capacity in outlying regions of the LHIN to better support complex ABI survivors to maintain function in their own community.
2. Develop a model to create specialized ABI services in a community-based supported housing environment for individuals with severe behaviour dysfunction requiring 24/7 supervision and who are currently residing in Champlain LHIN Alternate Level of Care (ALC) beds. This model will include a continuum of community based behavioural residential support services that leverages the expertise of TOH Behavioural Rehabilitation Services Outreach program and work currently being done by the Housing Working Group of the ABI Coalition.
3. Include care guidelines based on current evidence that addresses the needs of persons with moderate-to-severe ABI living in community settings, including those with co-morbid needs such as mental health and addictions.
4. Include an evidence-based proposal for how case management and system navigation resources should be deployed to best support client access to system resources.
5. Include an environmental scan of successful service delivery models in Ontario.
6. Propose system outcome indicators.

ii. Acquired Brain Injury (ABI)—A Health Priority

Acquired Brain Injury (ABI) is defined as damage to the brain, which may be caused traumatically from an external force such as a collision, fall, or assault, or through a medical problem or disease process which causes damage to the brain.[11] Many of these individuals will experience life-long challenges with cognitive, physical and behavioural deficits that will impact their ability to live healthy lives in our community. Due to the nature of their disability and other comorbidities or factors[12] these individuals are young and amongst the most vulnerable of our population.

It is estimated that 160,000 Canadians sustain traumatic brain injuries (TBI) each year[13] and over 6,000 will become permanently disabled with approximately half being left with physical,

[11] Toronto ABI network - This can include medical conditions such as anoxia, non-progressive tumour, infection, or brain aneurysm

[12] The additional presence of mental health and addiction challenges, and societal factors

[13] Brain Injury Association of Canada

cognitive/and or behavioural consequences severe enough to prevent them from returning to pre-injury lifestyles.

In Ontario there are 18,000 new cases of traumatic brain Injury reported each year.[14] In the Champlain LHIN, this would represent 6500 new cases of TBI per year. These numbers include individuals with mild TBI/concussion and those with moderate to severe injuries all requiring some degree of acute and rehabilitation services, including community based rehabilitation.

In terms of etiology, motor vehicle collisions (MVC) and falls comprise the most common cause of TBI across all age groups.[15,16,17,18] Falls resulting in brain injury disproportionately affect the elderly. With the expected growth of the seniors in Champlain by 2025, this may further increase the incidence of ABI.[19]

Individuals can be left with cognitive, physical, and psychological challenges that require ongoing rehabilitation and/or life-long support. ABI affects not only the individual but the family as roles and expectations are changed.

The World Health Organization International Classification of Functioning, Disability and Health (WHO-ICF) defines rehabilitation "as a coordinated process that enhances "activity" and "participation" aiming to optimize functioning and minimize the experience of disability of people with health conditions" (pg. 6).[20] Evidence suggests common themes which are important in a rehabilitation model. These include empowerment of the person, and the optimization of function to facilitate social participation. Rehabilitation outcomes include reducing impairment and optimizing participation and the role of the individual in society. Thus, when addressing rehabilitation it is important to keep in mind that it is a highly personalized process that occurs over many years across a continuum of services and supports and requires planning for transitions of care over time.[21]

iii. Framework for Community Based Rehabilitation

The ultimate goal of ABI rehabilitation is community integration.[22] Adults who survive a brain injury want to be able to integrate into their community, resume their vocational and social roles, relationships and participate in meaningful activities. Given the diversity of individuals, the nature of their injuries and subsequent impact on cognitive, behavioural, emotional, physical and psychosocial functioning, there is no one community based rehabilitation approach that will work for all individuals. The model should include a continuum of coordinated services and supports with the goal of maximizing community integration. The Ontario Neurotrauma Foundation (ONF) has recommended a general framework for

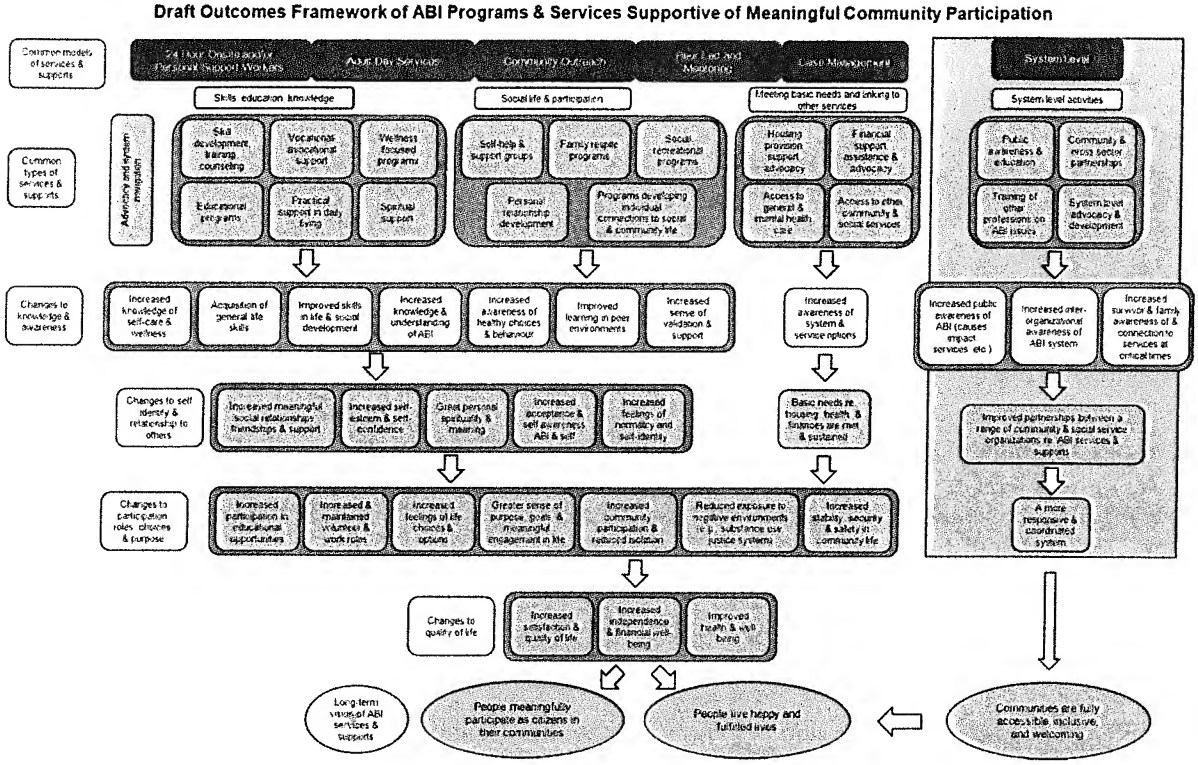
[14] Brain Injury Association of Waterloo-Wellington , A prevalence rate of 500/100,000
[15] Ontario Neurotrauma Foundation ,ERABI (2014)"Shown to account for approximately 75% of TBIs requiring hospitalization in Ontario from 1992 to 2002" (
[16] Ontario Brain Jnjury Association, 2012
[17] Colantonio et al., 2010
[18] Faul et al., 2010
[19] Champlain LHIN Integrated Health Service Plan 2016-2019
[20] Ibid
[21] Parsons, 2014
[22] ERABI, 2014

community based models, services and supports that incorporates system based activities to enhance community integration.[23]

In 2009 a group of Ontario community organizations, consumers, government members, academics and researchers formed the Community of Practice group with its main focus on "promoting full and meaningful participation of adults with ABI".[24] The Community of Practice group developed an outcomes framework of ABI programs and services supportive of meaningful community participation (see Figure 1). The framework outlines common models of services that exist in limited degrees in Ontario and that lead to outcomes related to meaningful participation. The "outcomes are expected but only under *the assumption* that actual programs and services have the capacity to meet the needs of individuals, are accessible, are well coordinated together, and actually do what they say they do".[25]

[23] ONF, Community of Practice 2010
[24] ONF, COP doc April 2010 pg 2
[25] ONF, COP p 7

Figure 1: Ontario Neurotrauma Foundation Framework



This framework recommends common models of supports and services not only applicable to individuals suffering from an ABI but also to their family members and caregivers. The objectives of all services are to provide interventions which:

- Enhance skills, education and knowledge
  - training, counselling, practical daily support
- Increase social life and participation
  - support groups, family respite, social recreational
- Meet basic needs
  - Housing, finances, access to general and mental health

The model supports that skill development training or social recreational programs can be offered whether someone requires 24 hour care or supported independent living. Expected outcomes of services vary from short term goal acquisition such as changes in skill, knowledge and awareness to ultimately changes in participation and improved health.

As noted in the discussion paper outlining the Community of Practice framework, "it is important to recognize that long term outcomes are not achievable merely through direct programs and services aimed at individuals and families".[26] System level activities are also

[26] ONF, Community of Practice, p 10

required in order for community participation to become a reality. System level activities include building community and cross-sector partnerships across multiple organizations, training other professionals on ABI issues, public education and awareness. As aptly stated, "if the system is not responsive and coordinated, many of the individual outcomes will be difficult to achieve. The goals of meaningful participation do not fall on the shoulders of individuals. While personal change is necessary, communities must also be open and welcoming for individuals to experience full citizenship" [27]

III. Current ABI Services in the Champlain LHIN

In March 2014 the ABI Coalition[28] commissioned a Needs Assessment to evaluate the acquired brain injury services provided in the Champlain LHIN.[29] This report recommended an integrated ABI care model for the Champlain LHIN that would be guided by an over-arching strategy that provides Champlain citizens with optimal re-integration in the community/home.

The report recommends integration and coordination of limited services.[30] Currently the Champlain LHIN has four separate publically funded ABI providers in the community: 1) the Robin Easey Centre, a transitional community based rehabilitation program that is part of The Ottawa Hospital, 2) Vista Centre Brain Injury Services, 3) Pathways to Independence[31] and 4) the City of Ottawa ABI Day Program.

Providers communicate with one another. However each service acts independently within its own mandate and accountability structures. Transition points are not viewed as seamless. There is duplication of services and waitlists are long. Rehabilitation, care and support for ABI clients and their families as they struggle with community integration could be improved.

Community based services can be broken down into the type of service offered to individuals. Services are not mutually exclusive and individuals may access different services simultaneously or consecutively depending on availability and need. Service providers were interviewed using a structured interview process.

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[27] Ibid, p 11

[28] ABI coalition is a group of funded and non-funded community based service providers whose mandate is to share information and identify gaps

[29] Parsons and Shah, 2014

[30] Ibid

[31] Pathways - direct funding accountability relationship is with the South East LHIN

1. Day Programs

The Ottawa area offers three adult ABI day programs.[32] Pathways and Vista also offer day programs in Renfrew and Cornwall. ABI Day programs are a type of adult day service program.[33]

Capacity for ABI day program spaces in Champlain is limited to 78 clients (see Appendix 2). Programs offer activities to engage clients and are geared to provide the necessary support to enhance participation in the program. Participation, however, is open-ended and as such there is limited capacity to accept new participants.

The City of Ottawa program functions under a Therapeutic Recreation model. In order to participate in the City of Ottawa Day Program, client goals must be specific and attainable and participation is time-limited, typically to one year.

The waitlist for Day Programs is difficult to determine as there is not a central intake process. It is estimated there are 40 individuals on a combined list for Ottawa Day programs.[34] All providers agree for the need to have a central waitlist and clear service criteria with an ability to match participants to the appropriate programs avoiding duplication of services. - All have waitlists

2. Outreach support (OR)/Supported Independent Living (SIL)

The Robin Easey Centre (REC) offers transitional community based rehabilitation therapy under the clinical leadership of a neuropsychologist and supervision of regulated health care providers.[35] The goal of the programs is to increase independence in the community. Average length of service is approximately 20 visits and they have approximately 25 individuals on their waitlist. Goals are reviewed weekly to ensure progress and services are adapted accordingly. Training is delivered to some clients via telerehabilitation technology in the client home.[36]

Both Pathways and Vista offer Supported Independent Living programs (SIL). SIL programs typically offer assistance to individuals living in the community in order to maintain their community living arrangement. Services and support can include assistance with activities of daily life (ADL), and instrumental ADLs.[37] Care is not offered under the supervision of regulated health care providers unless there is a specific issue that arises in which case they would consult with practitioners in the community. SIL workers will implement clinical care plans if they are available from regulated health care providers. Otherwise staff conduct their own evaluation and intervention plan with the client.

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[32] Provided by Pathways to Independence, Vista Centre and City of Ottawa

[33] CARF, 2016, An adult day service program that is non-residential, provides supervised care to adults of all ages in a supportive and safe setting during part of the day. An adult day services program provides or arranges for services that include, but are not limited to, therapeutic activities, nutrition, health and personal care and transportation. Adult day services programs typically deliver services through a social model and/or medical model. It enables the person served to live and engage in the community and provides the family system with an opportunity to fulfill daily responsibilities and for respite.

[34] Interview with administrators at Pathways and Vista

[35] e.g., Psychology, Social Work and Occupational Therapy

[36] Through Champlain LHIN HSIP support

[37] IADLs - budgeting, meal preparation/planning etc., support with medical services and medication administration, financial support to promote independence, maintaining relationships, skill development

3. Residential Services—Transitional Rehabilitation and Group Home

The Robin Easey Centre (REC) provides a transitional rehabilitation residential service. Pathways to Independence and Vista CBIS each offer a residential group home in Ottawa that provide 24/7 care, Each provider has five beds.

The REC admits 12-15 individuals per year in order to maximize independent living and community re-integration. LOS is on average 3-6 months and the current waitlist is 2-5 clients. Life skills counsellors work under the leadership and direction of a neuropsychologist and the supervision of regulated health providers in meeting the clients' rehabilitation goals. Residential clients receive both group treatment and individual treatment and goals are reviewed weekly.

The two residential group homes supported and managed by Vista and Pathways have waitlists exceeding 15 years, with 45 individuals currently on the waitlist. These group homes were at capacity when they opened and will continue to be so as the waitlist continues to grow. Unlike other residential services within the province there is little transition from these homes as there are few available supportive housing options in Champlain to allow transition. Individuals in these two group homes are considered life-long residents unless their care needs increase, requiring transfer to long-term care.

There are no residential homes for those with significant behavioural challenges and/or comorbidities in the Champlain LHIN and the provincial waitlist to access such a home is greater than 10 years with approximately 25 clients on the provinces' waitlist. In the mid-1990s when the province repatriated people from ABI services in the United States, two provincial providers in southern Ontario were established to meet the needs of the hard to serve ABI individuals throughout the province: Peel Halton Dufferin ABI Services in the Mississauga Halton LHIN (PHDABIS) and Brain Injury Services of Hamilton in the HNHB LHIN (BISH)offer three residential homes with a total provincial capacity of 24 beds for those with high needs. [38]

4. Supportive Housing

There are no ABI-specific, funded supportive housing environments in Champlain. Many individuals are unemployed and must access domicile/rooming house accommodations while waiting for more suitable accommodation. Waitlists are significant for City of Ottawa supportive housing.

Supported Independent Living programs can assist individuals with ABI living in supportive housing. Currently, barriers exist for individuals with cognitive impairment; a lack of stable environment and the structure and supervision available to support community living.

A recent initiative has begun as a result of the ABI Coalition Needs Assessment (2014). A Housing working group has formed with leadership from the Ottawa Inner City Health Inc. (OICHI) and ABI providers. The working group is developing a strategic plan to provide supportive housing in the Champlain LHIN, collaborating with non-ABI service agencies (see Appendix 3).

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[38] Life-long funding is allocated to the individuals, not necessarily to the facility. This has resulted in vacant beds, with no operational dollars to support the admission of another high needs client.

The Gardner St. Housing initiative has recently opened 34 apartment units. This initiative is a partnership between Ottawa Inner City Health Inc. (OICHI), the John Howard Society and the Royal Ottawa Mental Health Centre to assist homeless individuals with substance use and mental health issues. Over half of the residents of this housing facility have self identified as having also experienced an ABI with documented cognitive deficits. Training on brain injury, substance use and mental health is provided to onsite staff to better support at risk residents. Collaboration occurs with Vista Centre Brain Injury Services in providing this training to facility staff.

Both Peel Halton Dufferin Acquired Brain Injury Services in the Mississauga Halton LHIN and Dale Brain Injury Service in the South West LHIN have partnered with local agencies to identify and provide ABI specific supportive housing in their respective communities. Different levels of care and associated housing is required for a successful transitional model of care. The lessons learned in other provincial community rehabilitation services are that geographic proximity is an important consideration in providing services and support.

5. System Navigation in the Champlain LHIN

The Ministry of Health allocated funding for the implementation of ABI system navigation in each LHIN in 2009. It was proposed that a strategy of service coordination at the local level be developed. The concept behind system navigation was to facilitate access at a systems level, not at a case management level. The goal of navigation was the identification of service barriers and needs and the implementation of strategies to increase accessibility and service capacity. This would involve building partnerships and integrating ABI services across sectors.[39]

There are no standards for system navigation across the LHINs and each LHIN has developed their approach somewhat differently.[40] In the Champlain LHIN, the ABI System Navigator was envisioned to facilitate the linkages within the system, both between local service providers and across the province. The goal was to "develop a community-based coordination strategy that enhanced the capacities of the local service system to respond to the needs of individuals, families, and other stakeholders coping with the effects of ABI".[41]

The system navigator in the Champlain LHIN is the only provincial navigator accountable to the CCAC and the role is predominantly to assist individuals with ABI and their families within a case coordinator model. The role has not been established to address broader systems issues and this is a gap from the perspective of facilitating integration and creating capacity across health and social sectors.

System navigation resources are a key enabler to address the broader perspective of working with partners in mental health, addictions, community and social services, and the criminal

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[39] e.g., develop a number of complex case resolution tables that would bring together partners to address such issues as Alternate Level of Care at the hospital, or HSJCC, or MHA, or alignment with Behavioural Services Ontario & geriatrics, or housing, etc.

[40] Discussions with A. Scott (Provincial Programs Branch of MOHLTC), S. McKenna (System Navigator in Champlain) and V. Pepper (System Navigator in HNHB LHIN)

[41] Parsons and Shah, 2014 p 2

justice system in creating synergies across systems to enhance services for survivors of ABI and their family members.

6. Brain Injury Association of the Ottawa Valley

The Brain Injury Association of the Ottawa Valley (BIAOV) is a non-profit volunteer driven organization that does not receive public funding and helps acquired brain injury survivors reconnect with their environment by providing meaningful activities and opportunities for engagement. BIAOV is an affiliate member of the Ontario Brain Injury Association (OBIA) and works closely with OBIA on a number of projects such as caregiver training and a provincial Peer Mentoring Program. They offer a number of groups and programs to the community including peer and family support groups and a Step-Up Work Centre. This is a member directed day program that was designed to engage participants in meaningful activities.

The Brain Injury Association of the Ottawa Valley is a very active and successful organization and provides valued services to its members and its partners in Champlain.

The Brain Injury Association throughout Ontario plays a vital role within the community and often partners with community providers and the rehabilitation hospitals in providing education, training, advocacy and fund raising activities.

7. ABI Coalition

The ABI Coalition is a voluntary group of service providers, both publically and privately funded with the stated mission to provide leadership in furthering equitable, accessible, responsive, cost effective and quality services and support for persons living with the effects of an acquired brain injury (ABI) in the Champlain District. The Coalition has no direct reporting relationship. Its objectives include providing advice to the LHIN and MOHLTC, and providing a forum for information sharing. The Coalition also provides advocacy and undertakes specific projects related to ABI services. The group meets quarterly and does provide a forum for service provider discussion. It has created several system study documents which have informed the development of this report. The main focus of the group is information sharing.

8. Case Management

The cognitive and behavioural consequences of an ABI can be life-long and can impact the daily skills required to transverse complex social systems, such as health services, legal systems, employment sectors and housing. Not all clients require case management but for some complex clients it is required to facilitate care and transition through these various systems.

Case managers "proactively coordinate, facilitate, and advocate for seamless service delivery of persons with impairments, activity limitations and participation restrictions".[42]

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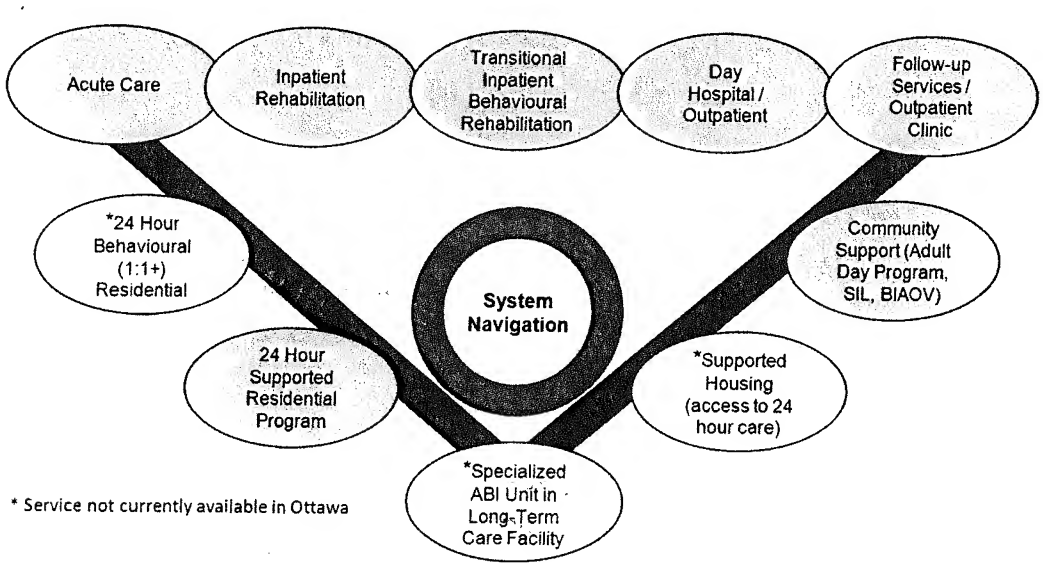
[42] CARF, 2016 - includes: initial and ongoing assessment, knowledge and awareness of care options and linkages, effective and efficient use of resources, individualized plans based on the needs of the persons served, predicted outcome, regulatory, legislative and financial implications

Unless the individual has third-party funding[43] or pays privately there is no case management in place for individuals who have an ABI in the Champlain LHIN. Individuals going through the public system encounter various providers who will assist them as they access each service but it is often fragmented and time limited.

A coordinated care plan is required to ensure access to appropriate service in a timely manner as the person transitions from more to less resource intensive services as they progress through the rehabilitation continuum. An evidence based model exists in the Hamilton Niagara Haldimand Brant (HNHB) LHIN. The Hamilton Health Science Centre (HHSC) has built their ABI programs around a case management model. These providers are known as Community Integration Coordinators (CIC).[44] Each person referred to the ABI program has an assigned Coordinator who facilitates care by navigating the client through various service agencies. The CIC will work with clients for as long as necessary and will resume service should the ABI client require it.. Community Integration Coordinators deal with the individual client but also liaise with the system navigator. This flow of information between CIC and the system navigator allows for an opportunity to identify potential barriers or gaps in community services and/or to gain assistance if dealing with particularly complex situations thus building stronger systems and allowing for better transition of care across the continuum.

Model of Current and Proposed ABI Services in Ottawa



Adapted from *A Framework for the Future Planning of Publicly Funded ABI Services in Toronto*. Toronto ABI Network, 2006

[43] e.g., motor vehicle insurance and/or WSIB

[44] Core functions of this role include: triage, assessment and intervention, clinical management, crisis management, monitoring, advocacy, service development, and discharge planning.

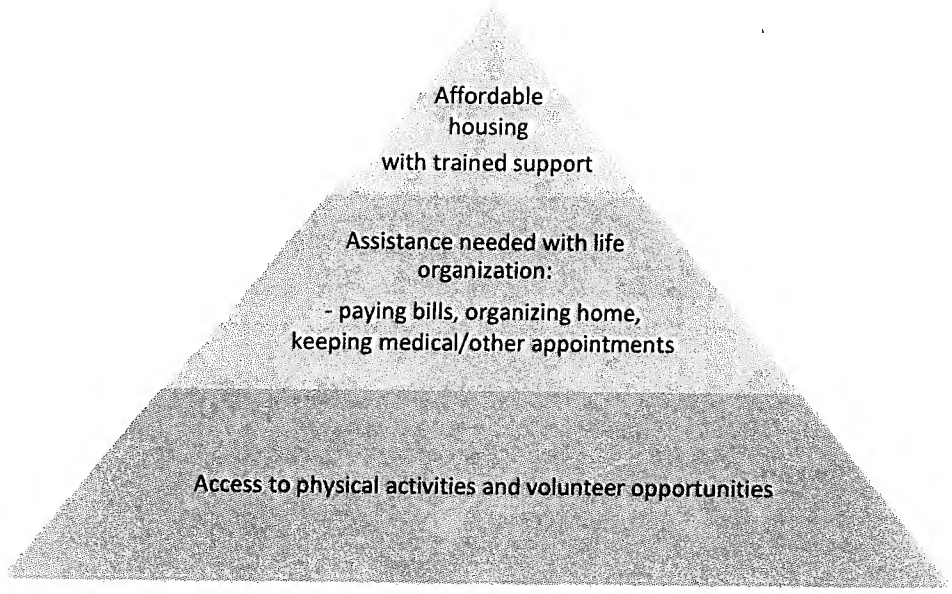
IV. Stakeholder Feedback: ABI Focus Groups

Information on existing gaps in ABI services was obtained from ABI clients and their family members. A focus group approach was used and feedback was obtained from 12 clients and 17 caregivers who currently access community based services in Champlain. Participants were organized into four groups which included caregivers from both rural and francophone communities. The mean length of time since injury of the participant was 6 years (0.5-20.5 years).

This group provided rich feedback based on their extensive experiences with the health and community support systems. The groups were structured to allow unique and fulsome participation of the clients with ABI and were led by trained facilitators.[45]

Questions were designed to address the identified gaps: housing, levels and types of community support, and meaningful activities. Participants were able to respond individually to the questions as well as in a group discussion format.[46]

Feedback from Individuals Living with an ABI: Priority Needs



In terms of housing issues, the most important issues from the participants' perspective were affordability, location, and trained services/staff in the home. Clients wanted support from a provider to assist with paperwork (bills, forms, mail), problem solving and organization and planning of home and community activities. Caregivers identified a need for additional support from providers with personal care, outings in the community and teaching behavioural strategies. A method to provide timely and regular information regarding access to services was also identified as an important aspect of any community based service by the participant group.

[45] Process designed and led by Dr. Mark Ferland, Neuropsychologist and trained Life Skills Counsellors
[46] Questions and respondent feedback (see Appendix 4)

V. Provincial Environmental Scan

i. Review of Successful Community Based Rehabilitation Agencies in Ontario

Four main ABI Community Based Rehabilitation providers in Ontario were contacted and facilities were reviewed as part of the environmental scan for this report. These providers were chosen as they represent comparators. These services are considered best practice in community based rehabilitation for moderate-to-severe ABI clients. The four providers were:

1. Dale Brain Injury Services in the South West LHIN
2. Peel Halton Dufferin Acquired Brain Injury Services (PHDABIS) in the Mississauga Halton LHIN
3. Brain Injury Services of Hamilton (BISH) in the Hamilton Niagara Haldimand Brant LHIN
4. Community Head Injury Rehabilitation Services (CHIRS) in the Central Toronto LHIN

A number of factors stood out across all agencies:

1. Each agency had a strong clinical focus both in terms of organizational structure and in providing client specific services.
2. All agencies had regular updated reviews of whether client goals were being met which allowed for services to be adapted accordingly.
3. All services were client-centered, surveyed their clientele (including family members) about what services to provide.
4. Each agency had built in transition plans that allowed for services to be increased and/decreased depending on need of the client at any given time across the continuum of services.
5. Waitlists were common across all agencies and all agencies provided some sort of wait list management.
6. All agencies incorporated a form of case management and/or coordination to facilitate care and transition.
7. All agencies emphasized the importance of education/training and advocacy in terms of building capacity, partnerships and improving accessibility to services including services from mental health, addictions and corrections. Program evaluation and research are primary organizational objectives in terms of guiding care and advocacy.
8. Revenue generation/fee-for-service activities occurred in each agency serving to support client-centred activities.

Clinical Care

All agencies had a strong clinical care component as part of their organizational structure and services. The Clinical Director is a Psychologist who establishes the clinical direction and ensures training of staff. All agencies employ regulated health providers (e.g., OT, SW, Psychology) that contribute to the care being provided and the training of front line staff.

Clients received integrated therapeutic care and goals were based on assessment/need of the client. The intervention team followed a treatment approach that was evidence-based. Goals were clinically relevant, meaningful and measureable which guided the intensity of resource allocation to the specific client. Other clinical services were sought on a consultative basis and specifically formal linkages were established with a Neuropsychiatrist. Each agency also had strong connections to the main Rehabilitation Hospital in their LHIN and was able to access services in a timely manner, particularly when a crisis emerged and tertiary level care was required.[47] The linkage with the specialty rehabilitation ABI program facilitated responsiveness of the community agency and alignment of treatment strategies during transition from hospital to the community. Agency leaders reported that care tends to be more seamless during transition. Planning is facilitated across agencies which reduces the disruption of care.

Each agency had a documented care plan in place for each client and regularly reviewed individual goals and outcomes.

Goal Attainment

The service mandate of all agencies is to identify, measure and monitor client goals. Client services are provided accordingly. Given the individualized nature of client goals, an interagency comparison of measures is not possible. However, each agency was committed to regular review of client goal attainment. Frequency varied according to type and resource intensity of service provision, from 3-6 months.[48]

All agencies also regularly review their services to ensure that they are meeting the needs of their clients in the most effective and efficient manner. The Brain Injury Service of Hamilton (BISH) recently underwent a program review. One finding recommended additional staff training to align with the clinical philosophy of the agency and to enhance skill development in their clients. As a result, BISH was able to report a dramatic improvement in client goal attainment over the past year in some of their very challenging clientele. Skill development improved and challenging behaviour was shown to decrease.

Transition Points

Each of the agencies was the main or sole provider of community based ABI services within their respective LHINS. It is believed that this has positioned these agencies to facilitate the development and implementation of best practices within community based rehabilitation. The services span the spectrum of care and support allowing for movement across the different service levels as the needs of the clients changed over time.

For example, all agencies offered Assisted Living[49] in a specialized residential facility. As clients reached their goals and developed skills that increased independence they were able to move to less intensive environments relatively easily: either Transitional Living Apartment Units, or Supported Independent Living environments managed by the agency. This allowed for

[47] Facilitated timely access to Physiatry or Neurobehavioural resources

[48] For example those in a more long term, structured setting such as Dale BIS SIL program had their goals reviewed every 6 months by the clinical team

[49] Staff on site providing 24/7 care or supervision

smoother transition of care, with the ability to offer appropriate service when required in a flexible manner with a minimal disruption to the client and their family. In the case of a client setback in ability where more intensive resources were required, client needs could also be more easily met.[50] Within the same agency, flexibility is maximized and disruption to care and support is minimized.

In addition to various housing options, all agencies offered a variety of interconnected services such as adult day services, drop in centres, and outreach programs. Individual and group programs were available to clients and family members.

All agencies also provided support and training to Long Term Care Homes in their communities. As individuals with a brain injury age and require more care than what can be met in the community, transition to LTCH will be required. Given that the agencies have committed to support and train staff in these different agencies, care of the client is enhanced not only during transition but afterwards. By providing cross training to other agencies, capacity is being built across the continuum of care and more clients with ABI receive appropriate service to meet their needs.

Wait List Management & Case Coordination

All agencies reported having significant waitlists for all aspects of their service and demand exceeds supply across LHINS. These agencies were the sole/main provider of Community Based Rehabilitation in their communities and waitlists were managed in a relatively consistent, effective manner. Individuals on the waitlist were not simultaneously on multiple waitlists across different agencies, and determining the appropriateness of the referral was managed in a timely manner. Support was offered while clients were on a waitlist, thereby minimizing crisis management. Generally each agency reviewed each referral within a specified time period and determination was made clinically and programmatically whether the referral was appropriate for the agency.[51] Once the referral is deemed appropriate, clients could access any day service or outreach group that was being offered while they waited for the specific service. Family members or caregivers were eligible to attend the family/caregiver support groups. Case managers or coordinators were also assigned to ensure that clients and family members had a contact person. Case managers were able to provide a solution focussed approach in a timely manner as issues arose.[52]

Each agency highlighted the difficulty of using a system navigator as the single point of entry as they do not complete the intake portion of the application process, nor can they manage the waitlist. Instead, agencies recommended that they collect the information and create a database that can be safely shared with the system navigator.

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[50] e.g., if more intensive staff levels were required short term, they could be put in place without moving the client or if necessary they could transition the client to more intensive resource allocation (from SIL to Assisted Living)

[51] e.g., PHDABIS has an intake committee that reviews applications on a monthly basis

[52] e.g., given the nature of the cognitive disabilities that may occur following an ABI, individuals may need assistance with how to renew OHIP cards, filling out ODSP forms, liaison if housing issues arose, etc.

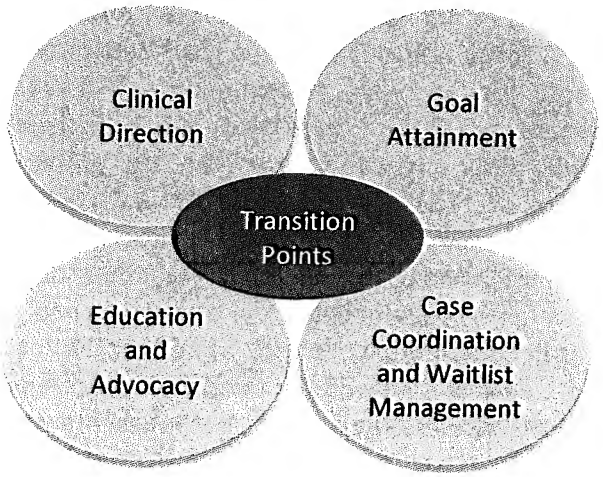
Education and Advocacy

All agencies reviewed demonstrated a strong education, training and advocacy focus. This facilitated building capacity within other agencies such as Long Term Care Homes, Mental Health and Addiction services, Corrections and/or Community and Social services on how to enhance understanding, compliance and participation from ABI clients. Advocacy was a core component both at an individual and system level within each of the respective LHINS.[53]

Community Based Rehabilitation agencies have also built partnerships with their local Universities and Colleges. They are able to offer practicum placements and internships as well as post-doctoral training opportunities to a variety of professionals and future front line staff.[54] Training programs create opportunities to build research and program evaluation into the agency. This promotes increased knowledge, skills and abilities of staff and supports best practice in the provision of ABI services.

The findings of the Ontario environmental scan of Community Based Rehabilitation models suggest the following guiding principles (Figure 4).

Figure 4: Key Guiding Principles of Successful Community Based Rehabilitation Programs



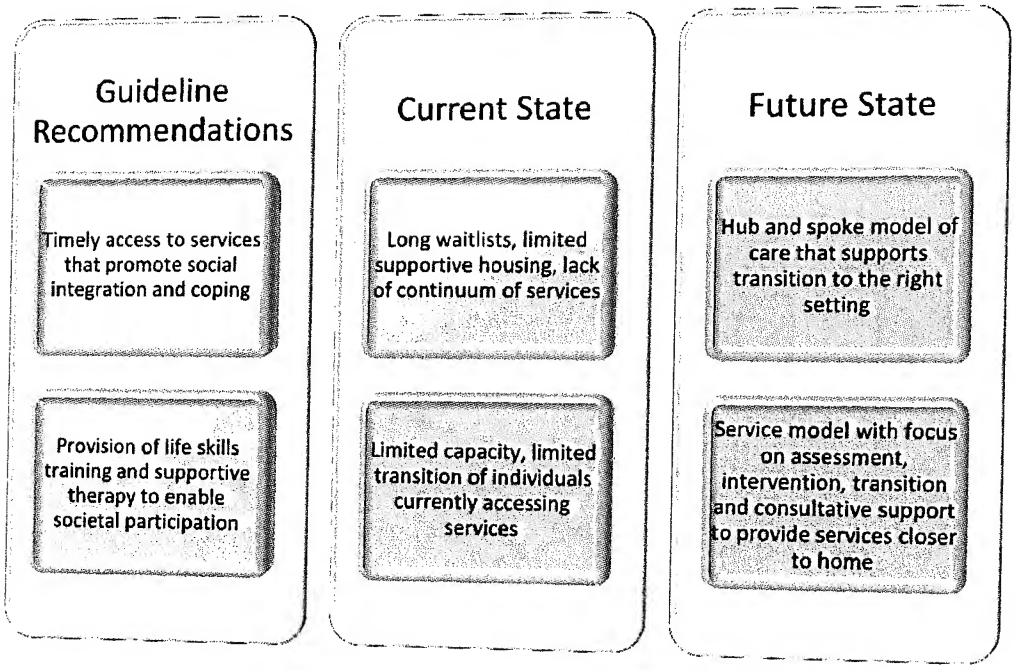
[53] e.g., offering prevention focussed education in primary schools, normalizing the effects of ABI etc.
[54] e.g., Social Workers, OTs, Psychologists; Rehabilitation Therapists, Counsellors, and Behavioural Therapists

ii. Best Practice Guidelines for Community Based Rehabilitation—Fundamental and Priority Recommendations[55]

An interprovincial initiative funded by the Institut national d'excellence en sante et en services sociaux (INESS) and the Ontario Neurotrauma Foundation (ONF) has led to the development of a Clinical Practice Guideline for the Rehabilitation of Adults with Moderate to Severe Traumatic Brain Injury.

This comprehensive review will guide future development of brain injury services across the full continuum. Specific to the community sector, there are a number of fundamental and priority recommendations for the sustainability of a community based rehabilitation model (Appendix 6 provides a full description).[56] A summary of best practice recommendations and the current and future state in Champlain is illustrated below (Figure 5).

Figure 5: Guideline Recommendations, Current State and Future State of the Champlain LHIN

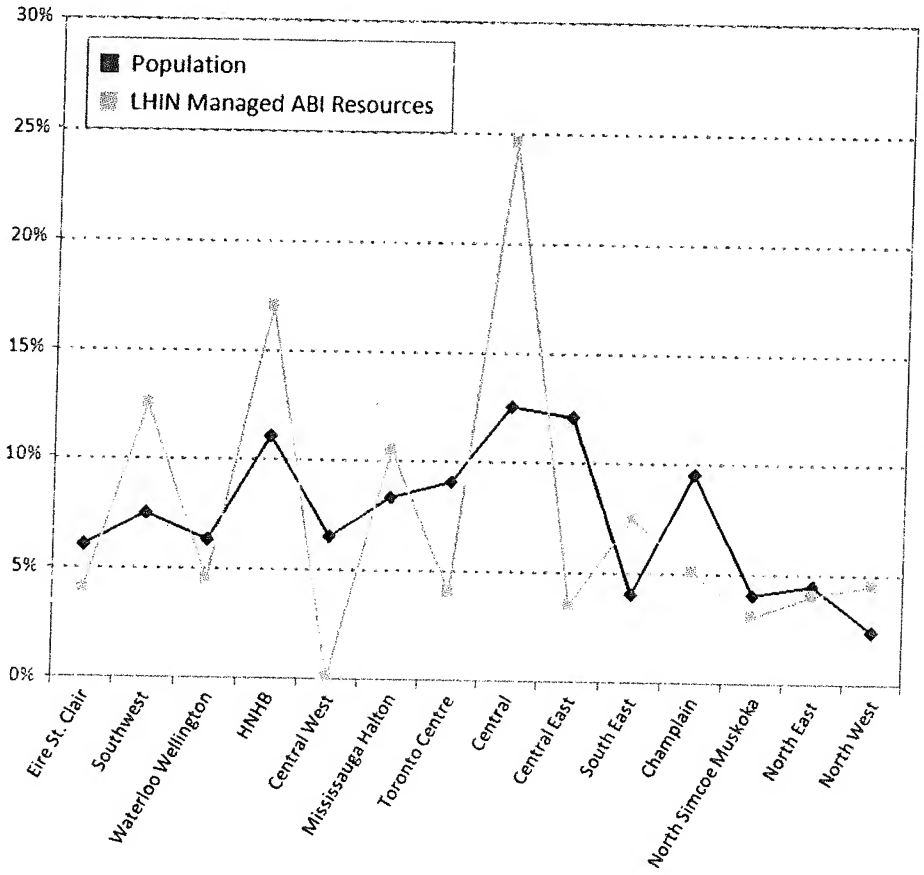


[55] INESS-ONF moderate to severe TBI guidelines
[56] INESS-ONF guideline currently in draft format

VI. ABI Services in the Champlain LHIN: A Need for Investment and Integration

A review of ABI services across the province revealed a number of gaps and opportunities to optimize the care and services provided to individuals with ABI and their families in Champlain. If we examine current resource allocation for LHIN funded community based services ABI services in Champlain relative to other LHINs in the province, a substantial discrepancy exists (Figure 6). Champlain has approximately 10% of Ontario's population but receives 4.6% of the overall provincial ABI Community budget. Provincial data sets support the fact that Champlain had the second highest percentage of TBI patients (41%) and the highest percentage of non traumatic brain injury patients (35%) amongst all LHINs with ALC days who also had psychiatric comorbidities.[57] These are many of the most complex patients who reside in hospital beds both in The Ottawa Hospital and throughout the Champlain LHIN.

Figure 6: ABI Resources by LHIN versus Population %[58]

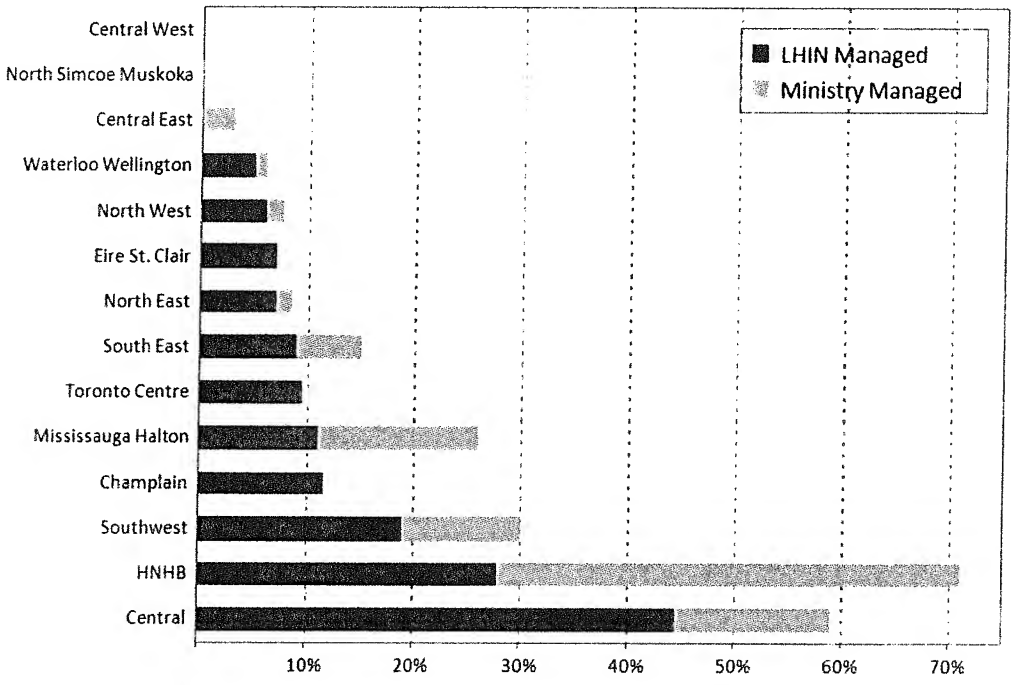


[57] Colantonio data extracted from Parsons report, pg 73

[58] Figure 6 and 7 extracted from presentation, 2009 MOHLTC, Provincial Programs Branch, Community Services Present and Future

The Champlain LHIN is also one of only three LHIN regions that receives no ministry managed ABI funds (Figure 7).

Figure 7: Current Service Distribution—ABI Services in Supportive Housing



There are no funded ABI psychiatric services in Champlain.

Overall, when examining the needs of the ABI population of Champlain, there are significant issues of access to the right service at the right time. Additional investment, more formal, structured integration of existing services and consistent application of the most current evidence to support care are the important elements of a system of care for individuals with ABI and their families; a system that they will experience as *coordinated, integrated and accountable where and when they need it*".[59]

i. An Integrated Approach to Community Based Rehabilitation

ABI survivors and their families living in Champlain experience:

1) Lack of access to an integrated continuum within existing services and a lack of access to the full spectrum of services that should be present in a successful community based rehabilitation system.
2) Lack of Supportive housing for:
    a. the most behaviourally/cognitively complex individuals and

[59] IHSP Champlain 2016-19, pg 19

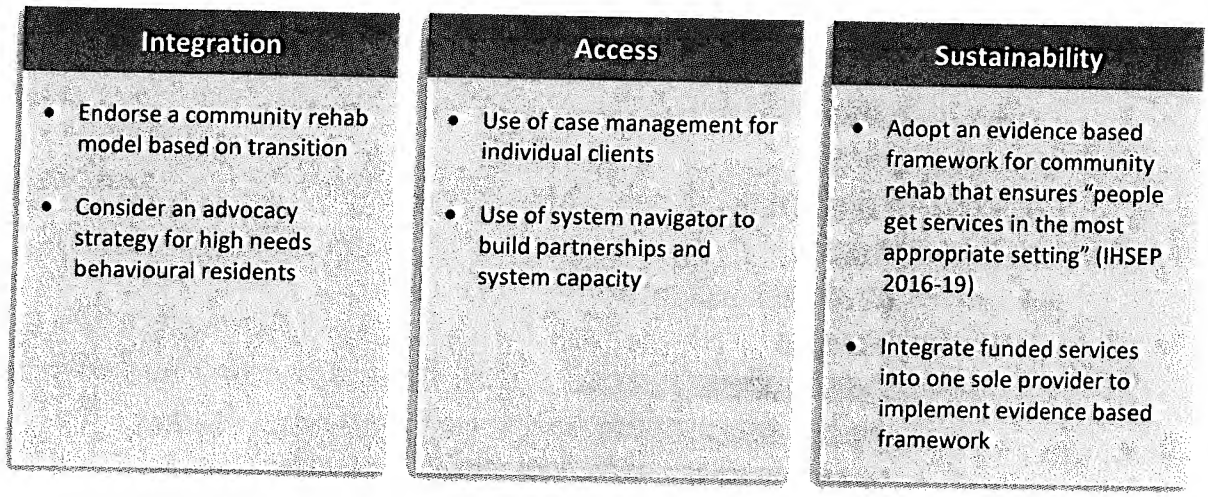
b. those individuals with different levels of care needs with the potential to be successfully supported in less resource intensive community environments

3) Lack of coordination of services and waitlist management.

4) System navigation challenges that are highlighted by the lack of cross-sector partnerships required to serve populations with complex, life-long needs.

Recommendations at a Glance

Long Term Objectives:



ii. Single Community Based Rehabilitation Provider to Enhance Integrated Care

Individuals with acquired brain injury require ongoing services for many years after the initial injury or illness. Evidence supports the fact that improved functioning does take place over time when the appropriate services and care are made available at the right time.

Engagement with the publically funded service providers for purposes of developing these recommendations highlighted that each offers similar types of services. As distinct entities, each provider operates within its mandate and vision on how services are offered and has developed unique processes to support service delivery.[60] Agencies maintain a high level of accountability to both their funders and their clients but their separate and distinct operational structures create barriers to transition of individuals through various levels of care with minimal duplication and delay. The current accountability structure within the sector does not include a lead agency mandate for system development of community based rehabilitation (CBR) for moderate-to-severe ABI individuals and their family members.

[60] Processes such as intake process, waitlist management, assessment and care plans

Other LHINs have a sole provider of community based rehabilitation.[61] This structure supports integrated care and effective coordination and management of Community Based Rehabilitation.

Recommendation 1: It is recommended that the Champlain LHIN consider integration of publically funded ABI providers to create one main provider, either as a fully integrated single entity or in a lead agency model.[62] The organization of services under one provider that has strong clinical leadership, supervision, and program direction will facilitate transition of individuals with ABI from acute care to community. Services would be provided across a continuum dependent on individual needs from transitional rehabilitation to assisted living and various outreach support services including adult day programs and supported independent living. This sole or lead provider could be viewed as the system hub, with a mandate to provide accessible services across the entire Champlain LHIN (see Appendix 5 for sample organizational structure).

Recommendation 2: It is recommended that the service hub have clinical direction and leadership of a Neuropsychologist along with a designated, permanent clinical team that could provide primary clinical service, consultative support to other providers and capacity building within and across sectors. The team should include regulated health care providers and rehabilitation professionals with special training in cognitive rehabilitation strategies.[63] It is advisable to develop a strong linkage with the hospital based ABI rehabilitation team and other specialists such as Psychiatry and the Behavioural Rehabilitation Service to ensure timely access.

This single Community Based Rehabilitation provider model will provide a structure where individual client goals and needs are periodically evaluated and services adjusted accordingly in order to facilitate transition for clients through the continuum from higher to lower resource intensive environments. Opportunities for program evaluation, research, training/education and advocacy would also be enhanced.

Opportunities would exist to build a Centre of Excellence in Community Based Rehabilitation for moderate-to-severe ABI clients and their families/caregivers. Student placements and training experiences for various professional groups increase service capacity while trainees are under supervision.[64] Ongoing program evaluation and research can also be conducted more readily when students are involved. This provides opportunities for grant proposals to external sources for further funding of program evaluation and research.[65] By building expertise, training and

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[61] e.g., PHDABIS within the MH LHIN, Dale BIS within the SW LHIN, BISH within the HNHB LHIN, and CHIRS within the Central LHIN

[62] e.g., combine Pathways, Vista BIS, Robin Easey Centre and the City of Ottawa Day program

[63] Such as Occupational Therapists, Social Workers, Speech-Language Pathologists, Therapeutic Recreation, Life Skills Counsellors, Behaviour Therapists, Rehabilitation Therapists

[64] e.g., students from U of O in Psychology, Occupational Therapy, Nursing, students from Carleton U in Psychology and Social Work, as well as students from St. Lawrence College in the BST program, etc.

[65] e.g., Trillium Foundation, ONF, CIHR, etc.

advocacy activities could be carried out strategically throughout the Champlain LHIN to both ABI and non-ABI organizations.[66]

Transitional care is fundamental to this model and will provide greater access to services across the continuum. Case management is required to support client transition through and across different services and sectors. The role of Case Manager could be modelled after the best practices of the Hamilton Health Science Centre model, where a therapist is responsible for intake coordination, waitlist management, and communication between clients/families and providers.

This single provider model would allow for the collection of more accurate performance indicators, including utilization indicators, clinical performance measures of quality.

Broader system level opportunities to build capacity and efficiencies across sectors should be the primary function of the ABI System Navigator. It is recommended that the ABI System Navigator position be located within the sole/lead provider organization and that the role be refocused on facilitating cross sector service integration in housing and supported living. The main role of the system navigator should be the evaluation, support and development of appropriate systems and partnerships across sectors within the LHIN. In order to achieve these goals, the Navigator would require the broad perspective and competencies of working with partners in mental health, addictions, community and social services, and the criminal justice system in creating synergies across systems to enhance services for survivors of ABI and their family members.

iii. ABI Services in Supportive Housing

A. Specialized ABI Services for Individuals with High Needs

The Champlain LHIN does not have a community facility that provides 24/7 specialized services for individuals with severe behaviour dysfunction. These individuals reside in inappropriate settings including hospitals and long term care.[67] This approximate 1% of individuals with severe injuries are the few but hard to serve, who cannot be managed in any current level of community setting.

Recommendation 3: It is recommended that the Champlain LHIN consider an advocacy strategy with the Ministry of Health and Long Term Care and the Ministry of Community and Social Services for the investment of capital and operational funding to create a specialized ABI community-based supported housing facility with a capacity for six residents, as part of Champlain's regional Community Based ABI services.

As more individuals survive the initial injury there will always be a percentage of people who have challenging behaviours that will not be able to live in the community without specialized care and support. It is unlikely that the provincial waitlists for this type of service will decline and additional capacity in Champlain would allow these individuals to live in a community setting that meets their needs as close to home as possible.

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[66] e.g., LTCH, CAMH offices, Community Centres who address addictions

[67] Individuals in hospital with ALC days > 1000, estimated annual cost $400,000-$500,000

This specialized service would allow individuals to move through the continuum of care in the most efficient and flexible manner possible. With the expertise of a clinical team and specialists in our community,[68] skill development and behavioural control can be addressed and managed effectively with positive functional outcomes for clients.

In the short term, it may be possible to transition one to two individuals with high-intensity needs from hospital to one of the group homes when a space becomes available. This would require a pilot project with one-time resources allocated to transition individuals to the required level of care and supervision.

Recommendation 4: It is recommended that the Champlain LHIN consider an increase in one time funding to the Robin Easey Centre for a pilot project to identify and create transitional plans for current community residential clients.

Successful implementation would create capacity for current community residential facilities to accept high needs client currently residing in hospital.

B. ABI or Attendant Services in Supportive Housing

In conjunction with reorganizing services under one agency, it is also imperative that the ABI Coalition Working Group continue to develop a supportive housing network across various sectors.[69] Without appropriate housing for individuals to live in and transition to, rehabilitation ceases and services become blocked.

Various levels of housing needs are required:

a. assisted living with 24/7 level of support (for those who would otherwise go to Long Term Care Homes but who could with rehabilitation and time become more independent in their functioning; could be a combination of individual and group living spaces)
b. aggregate supported independent living (i.e., apartments located in the same building with individuals requiring daily support, but not 24/7 level of support; may or may not have communal space)
c. transitional level of care for those who require further rehabilitation in order to achieve independence in the community
d. supported independent living in the community (for those who can live fairly independently but may require some support to ensure that they will continue to live safely

Recommendation 5: It is recommended that the Champlain LHIN consider additional annualized operating funding increase to the current residential provider to accept high needs clients.

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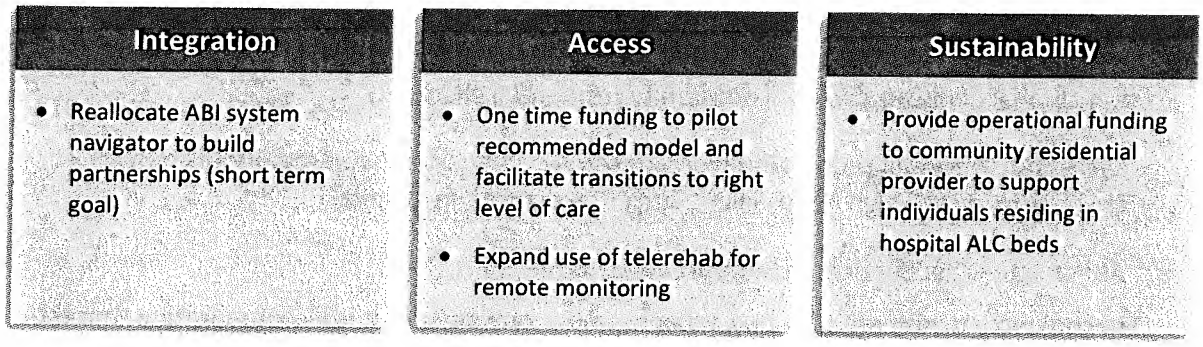
[68] TOH ABI program & Psychiatry

[69] Including Ottawa Inner City Health, the Royal Ottawa, John Howard Society/Elizabeth Fry Society, City of Ottawa, and private developers

This would accommodate the transition of 2-3 individuals requiring 24 hour support currently residing in Champlain ALC beds.

Recommendation 6: It is recommended that the plan for integration of services includes reallocation of the current funding and accountability for the ABI System Navigator role to the Robin Easey Centre with a mandate to facilitate cross sector service integration in housing and supported living.

Recommended Short Term Objectives:



Supporting Integration and Improvement:

This report recommends a restructuring of services offered in the LHIN and there will continue to remain a role for a network of ABI service providers (public, private, volunteer) within Champlain. This group could function as a regional network to facilitate educational opportunities, to promote advocacy for clients and caregiver support and to liase with the LHIN and other cross sector community partners.

This would represent a change of focus for the current ABI Coalition and would require agreement of the members and some changes to the existing terms of reference for the group.

VII. Conclusion

Community-based rehabilitation services for individuals with moderate-to-severe acquired brain injury needs to be considered a health priority in Champlain. As highlighted in the consumer focus groups and discussions with the publically funded agencies, there is a desire in Champlain to move forward and create a continuum of care that meets the needs of those suffering from moderate-to-severe ABI and their family members.

The prevalence of ABI in the Champlain LHIN is higher than the Ontario rate[70] with resultant demand on existing community based rehabilitation services and support sectors. According to a 2009 report, the Champlain LHIN had the highest median ALC days for both traumatic and nontraumatic brain injured survivors.[71] The existing community based ABI services are focussed

[70] Parsons, D and Shah N, 2014, pg 14, 2.2 per 100,000 TBI Champlain compared to 1.8 per 100,000 Ontario
[71] ibid pg 15

on providing life long support; however evidence suggests that a transitional community model can result in a people centred approach that results in "meaningful participation as citizens in their community".[72]

Gaps exist in current service models and funding in Champlain. There is limited access to community based support for all individuals with ABI, particularly those in rural communities. There is a need for integration and innovation both within the ABI service sector and across sectors to build capacity.

Provincial counterparts[73] have demonstrated the efficacy of an evidence based transitional model of community based rehabilitation services. Current practice guidelines support a hub and spoke clinical model of care that facilitates transition of the individual to the right setting.[74]

Integration of funded services under one service provider and investment in an enhanced model of care will result in better care, improved capacity for service provision and improved access throughout the Champlain LHIN.

A step wise approach will be required. For 2016-17, a transition team with clinical expertise[75] can identify and create transitional plans for current residential clients in ABI funded facilities and invest in clinical support to assist with transition of 2-3 ABI residential clients to a less resource intensive community setting. This creates capacity in ABI residential homes for individuals with ABI currently residing in hospital. One time and operational funding[76] will be required to support this project and initiate a change in philosophy toward transitional community services.

Integration of funded ABI providers into one single community based provider will bring Champlain into alignment with provincial comparators and will help to create a sustainable, accessible and integrated system for people with ABI.

Although this report focussed on community based rehabilitation services for those with moderate-to-severe ABI, the framework presented can and should form the foundation for all ABI services in Champlain. Once the framework is in place, specific transition points from childhood to adult services, from adult to geriatric services can be more fluidly addressed. Also, the needs of those suffering from the persistent effects of post-concussion can be better served once a framework is in place.

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[72] Ontario Neurotrauma Foundation, April 2010, An Outcomes Framework for the ABI Community of Practice, p 6
[73] PHDABIS, BISH, CHIRS
[74] INESS-ONF Clinical Practice Guideline for Moderate to Severe TBI
[75] and including the ABI system navigator
[76] One time funding and operational increase

Appendix 1

List of Contributors

- Vista Centre Brain Injury Services – Tammy Kuchynski, Program Manager and David Walls, Executive Director
- Pathways to Independence – Lorrie Heffernan, CEO and Darlene McKenny, COO
- Robin Easey Centre – Dr. Mark Ferland, Clinical Leader and Wendy Spenst, Natalie Belanger, Johanne Larente, Andrejs Mazpolis, Life Skills Counsellors
- System Navigator Champlain LHIN – Suzanne McKenna
- Brain Injury Association of the Ottawa Valley – Wendy Charbonneau
- The City of Ottawa ABI Day Program – Kate Jacobson-Lang, Coordinator Therapeutic Recreation Programs
- TOH Behavioural Rehabiliation Service – Dr. Steve Joncas, Clinical Leader and Una Wallace, Rehabilitation Therapist
- TOH ABI Outpatient Clinics – Drs. Deanna Quon and Shawn Marshall
- Champlain LHIN Senior Integration Specialists – Kevin Barclay and Rod Olfert
- Ottawa Innner City Health Inc. (OICHI) – Wendy Muckle, Executive Director
- Dale Brain Injury Services in London, ON – Sue Hillis, Executive Director and all managers, clinical staff and clients at DALE and Cornerstone Clubhouse
- St. Josephs Health Care, Parkwood Institute, London, ON – Julie Gilvesy, Director Rehabilitation Programs and Omer Vandevyvere, Regional Coordinator ABI Services Southwestern Ontario
- Peel Halton Dufferin ABI Services in Mississauga, ON – Al McMullan, Executive Director and all senior administrative and clinical staff and clients at PHDABIS
- Brain Injury Services of Hamilton, ON – Candy Sarraf, Director Rehabilitation Services and all managers and clinical staff at BISH.
- Hamilton Niagara Haldimand Brant ABI System Navigator – Veronica Pepper
- HNHB LHIN Director, Access to Care – Rosalind Tarrant
- Hamilton Health Sciences Regional Rehabilitation Centre – John Zsofcsin, Manager ABI Services and Dr. Diana Velikonja
- Community Head Injury Rehabilitation Services, Toronto, ON – Hedy Chandler CEO, Dr. Carolyn Lemsky, Clinical Director and Danny Caplan, Director of Operations and the managers and clinical staff at CHIRS
- Ministry of Health and Long Term Care – Ann Scott, Senior Program Consultant, Provincial Programs Branch (PPB)
- Ontario Neurotrauma Foundation – Corinne Kagan, Senior Program Director
- ABI Connect Communities, BC – Patti Flaherty President and COO

Appendix 2

Capacity for ABI Day Program Spaces in Champlain

ABI Day Programs in Champlain LHIN

Agency	Days/Week	Number of Clients	Types of Clients	Waitlist
City of Ottawa - Therapeutic Recreation program	2	15	ABI 21-65 years	Not available
Pathways - Ottawa*	4	20	6 residential	40 combined with Vista
Vista - Ottawa	2	18	5 residential	NA
Brain Injury Association of the Ottawa Valley (BIAOV)*	Various programs offered M-F	50-60	Mild TBI to moderate-severe ABI	No waitlist
Pathways - Renfrew	3 (+ 2 days OR)		ABI adults	11
Vista - Cornwall	3	25	ABI adults	0

* Not funded by Champlain LHIN

ABI Outreach/Supported Independent Living Programs in Champlain LHIN

Agency	Number of Clients	Number of Staff	Length of Service/Stay	Waitlist
Robin Easey Centre	65-79	3 FTE	20-25 visits	25
Pathways - Ottawa*	38	2.5 FTE	2.6 years[77]	NA
Vista - Ottawa	95	6.65 FTE	Not available	35
Pathways - Renfrew		1 FTE (shared with Day Program)		7
Vista - Cornwall	9	1 FTE (shared with Day Program)		2

* Funding from the South East LHIN

[77] Parsons and Shah p 27

Appendix 3

ABI Housing Working Group Report

The ABI Housing Working group has worked strategically to achieve the following deliverables:

1. Identify supportive housing providers who are amenable to partnering with the ABI community service providers to develop an integrated model of supportive housing and ABI services in Pembroke and Ottawa (Cornwall area under development). In addition, a relationship has been established with OCH and CCOC who are the main providers of affordable public housing.
2. A pilot project is underway in Ottawa with John Howard Society at their Gardner Street housing program to provide ABI specific services to residents through partnership with the staff. Seventy five percent of residents at Gardner are living with ABI. This pilot includes documentation of the kinds of supports, knowledge and activities needed for the provision of integrated ABI and supportive housing services. It is anticipated that this model will provide us with the knowledge needed to flesh out the model of service needed to justify funding which can be used to service more housing programs.
3. Education (ABI for housing workers and SUBI training) sessions have been held, evaluated and, planning is underway for more sessions. There has been a strong uptake from the supportive housing providers which is encouraging.
4. Completion of the first version of the housing continuum for people living with ABI (see next page).

Champlain ABI Housing & Care Continuum

Values & Principles:

- Services provided should reflect the choice of the recipient
- Services should promote recovery, independence and community integration to the greatest extent possible
- Services should be appropriate, accessible and adhere to the best available evidence guiding ABI treatment and care
- Service providers should work together collaboratively to insure that recipients are able to transition easily between services

The Care Continuum for ABI in Champlain:

The objective of the Champlain ABI Housing Working Group is to develop a continuum of housing and support options to respond to the many and varied needs of persons living in Champlain with the aftereffects of ABI. In articulating an ABI housing continuum for Champlain, it is the intent of the Coalition not only to describe the kinds of housing and services which are needed but, to articulate how the ABI Coalition works to bring together partners within the community and supports them to work together on behalf of people living in our community with ABI.

Impact of ABI	Models of Suitable Housing	Partners/Service Providers	Role of the ABI Coalition	Role of Housing Sector
Mild ABI without obvious physical impairment, able to manage most aspects of life without assistance *(urban or rural)*	Independent Housing alone or with family or friends *(Youth likely with families, may need to change in time, little need for ABI specific services)*	Access to family doctor or ABI Navigator for advice if issues arise Role for community awareness and education initiatives	**None** - housing and services exist and are readily accessible – need to be sensitive to rural and other special needs Building capacity-link to housing sector to include in education and other initiatives	Can seek assistance from Housing Help or Action Lodgement if help required with housing search Market rent housing Private Market with rent sup. OCH CCOC or other RGI options for those with limited income
Mild ABI without obvious physical impairment but with mental illness/and or Substance use which affects housing stability *(urban or rural)*	Independent Housing with support of family or friends Supported Housing (scattered site) Supported Housing (scattered site) with mental health or SU ICM *(?? Youth, seniors)*	Access to ABI Day Program to address specific deficits Access to Mental Health care Access to Substance Use treatment (SU or CD) Intensive Case Management (CMHA Ottawa, SHCHC) ACTT Supported housing providers including housing based case management services	**Capacity Building** Need to partner with housing providers, mental health and addictions community Need training to support persons living with ABI, mental illness and addictions Need Access ABI services as consultant services Need to identify which housing providers are housing people with ABI	OCH CCOC Options Bytown Salus CMHA Sandy Hill ICM Daybreak Etc

Impact of ABI	Models of Suitable Housing	Partners/Service Providers	Role of the ABI Coalition	Role of Housing Sector
Moderate ABI without significant physical impairments but with significant cognitive impairments **without** mental illness or substance use which affect ability to obtain and retain housing *Access in rural setting?*	Independent housing with support of family, friends and caregivers Supported housing (scattered site) with ABI worker and caregivers Congregate living as a stepping stone to recovery or permanent housing	Access to range of supported housing options Access to ABI worker Access to caregivers Access to ABI day program Access to rehabilitation options Long wait for Rehab or Robin Easey	**Develop ABI Community Support Service Model** ABI sector to partner with supported housing providers May need access to CCAC or attendant care services Partner with rehabilitation services to determine likely benefit	Market rent Private market with rent supp OCH CCOC Other housing providers Dom Hostels?
Moderate ABI without significant physical impairment **with** mental health and substance use issues and significant cognitive impairment	Supported housing (scattered site) with ABI, mental health and addictions service providers Congregate living with support from ABI service providers, access to mental health care, addictions etc.	Housing providers Dom Hostels Homes for Special Care ABI Outreach staff ABI Day programs (?) Mental health care (may include ICM, ACTT) Accessible substance use treatment services	**Integrated ABI Community Support Service Model Delivery** Access to ABI community support team Need to partner with housing, mental health and substance use providers, to create team to support high intensity of care needs, respond to crisis etc. May need access to CCAC May need access to rehab programs	Supported housing providers Congregate living housing options a priority for development Dom Hostels Highly underserved group may be inappropriately housed such as young individuals placed in LTC

Impact of ABI	Models of Suitable Housing	Partners/Service Providers	Role of the ABI Coalition	Role of Housing Sector
Severe ABI with significant physical impairment, without signficiant mental illness or substance use	Supported housing (scattered site) with ABI, attendant care Congregate living (ABI specific) Congregate living (Not ABI specific) Long term care, retirement homes	Supported Housing providers ABI Housing providers Attendant care providers ABI Day programs Long term care providers	Promote Development of ABI Specific Housing Access to ABI community support team Partner with housing providers to engage clients to participate in community and rehabilitation Access to CCAC or attendant care	Pathways CCOC/OCH Long Term Care Retirement Homes Accessible dom hostels (ie Kanata) with enhanced services High probability of ALC in Hospital, at home with elderly parents, underserved by ABI services high potential for inappropriate or unsustainable housing Action Item link to Bruyere
Severe ABI with significant physical impairment, mental health or substance use issues	Congregate living (ABI specific) Long Term Care Hospitals	ABI organizations ABI Housing providers Long Term Care Mental health and addictions providers (ACTT)	**Collaboration between sectors and organizations to create solutions to housing needs for those considered hard to house** What is optimal access to mental health services and substance use? Access to CCAC or attendant care services	Housing sector needs to collaborate with other sectors to create individual housing solution for individuals with complex needs

System Level Challenges:

- Options for timely discharge from hospital (access to short term options with long term housing plan appropriate for that individual)
- Currently concentration of ABI resources in treatment and rehabilitation, need to develop capacity for life long community support services
- Need for specialized expertise for youth, seniors, people living with SMI and substance use
- Need for integrated community support system which includes housing, mental health, substance use with ABI expertise
- Need to look at rural access issues
- Need to take into consideration overall population of clients not those currently in services
- Need to consider wide diversity of approaches as seen in other areas of the country, increase models that support independence or provide as needed supports

Appendix 4

Focus Group Results

Demographics

	Patients	Caregivers
Number of Focus Groups	2	2
Number of Attendees	12	17
Gender		
Male	58.3%	5.9%
Female	41.7%	94.1%
Residence Location*		
Rural	0%	37.5%
Ottawa	100%	63.5%
Funding Available*		
Yes	40%	31.2%
No	60%	68.8%
Currently Using Services*		
Yes	87.5%	81.2%
No	12.5%	18.8%
Mean Length of Time Since Injury	6.0 years (0.5 to 20.5)	11.9 years (2.5 to 36.0)

* Not all respondents provided information on residence, funding or services

Patient Responses to Focus Group Questions

1. Regarding persons with ABI, the most important housing issues are:
   - Lost cost
   - Location
   - Trained services in the home
   - Reduced wait time
   - Separate subsidy living space
2. If persons with ABI could have the assistance of a general "helper person" for a few hours a week, what would be the most important ways to use the services?
   - Paperwork (bills, forms, mail, etc.)
   - Problem solving (trouble shooting, solutions)
   - Organization (planning activities, time management)
   - Accompaniment to appointments

3. If persons with ABI had access to a general "helper person", then the most acceptable contexts to get that help are:
   - Home 1:1
   - Electronic communication
   - Outside home 1:1
   - Group outside home (health care agency, public setting)
4. The three most important things persons with ABI tend to look for in non-family pastimes that can give meaning to life are:
   - Physical activities
   - Volunteering
   - Formal knowledge/academic opportunities
5. There is often a waiting period to access ABI services (that is, you can be on a waiting list). The most important ways this can be more acceptable/bearable are:
   - Regular accessible information about position on wait list
   - Support group for people on wait list
   - Strategies/information on how to cope via website
   - Access to intervention/emergency services
   - Prioritization by need

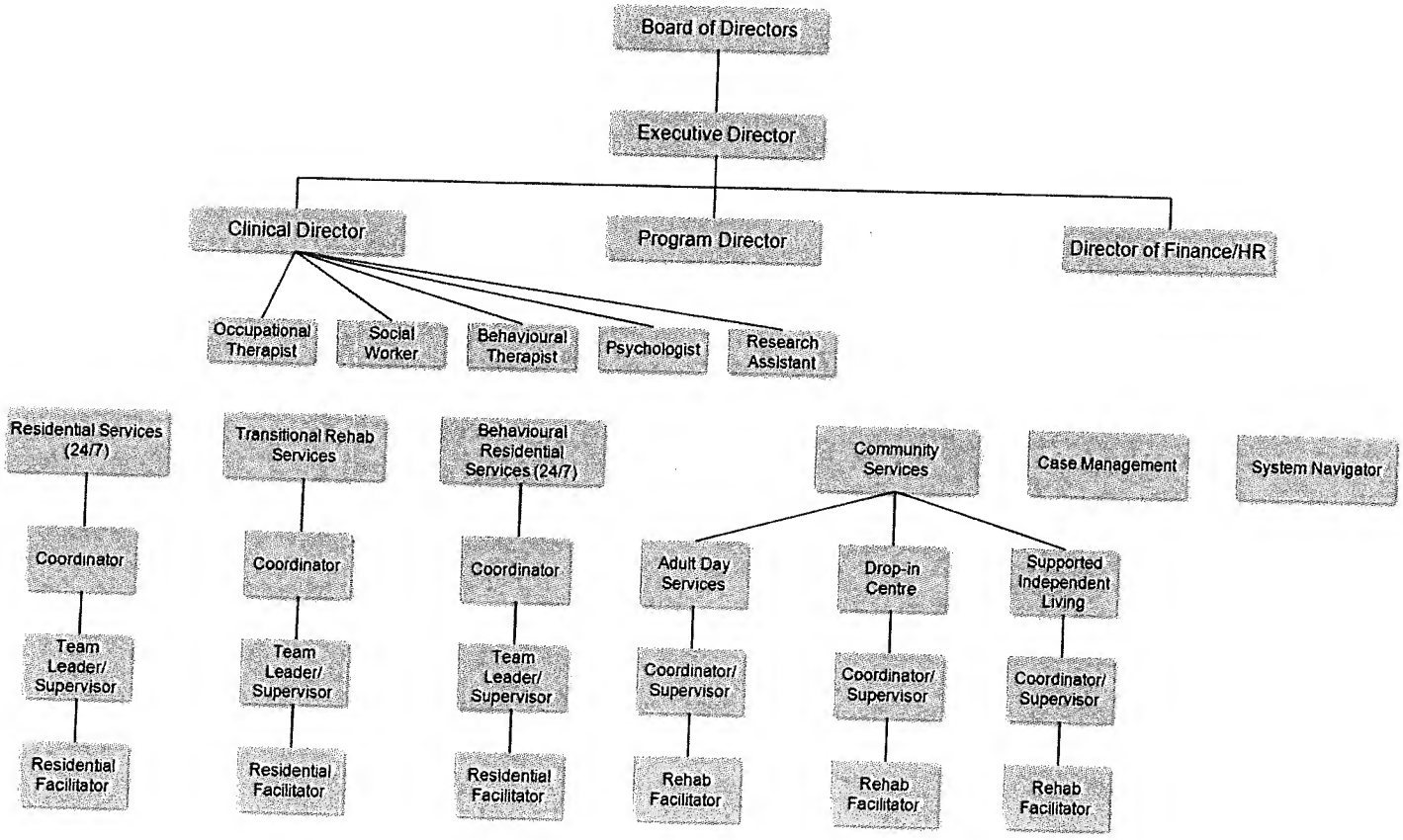
Caregiver Responses to Focus Group Questions

1. What do you feel are the most important housing issues for persons living with ABI?
   - Affordable (e.g., subsidized costs)
   - Location (access to community services/resources)
   - Trained staff (knowledge of ABI, safety, ability to assess client needs)
2. For a family member who cares for someone with an ABI the most important resources the family member would benefit from are:
   - Respite
   - Liaison/advocate for crisis situations (e.g., hotline) and to help with coordination of services
   - Access to family support group
3. If you had the opportunity to have a general "helper person" for a few hours every week to assist with the care (i.e., hands-on assistance, supervision etc.) of your family member, what would be the most important ways you would make use of such a person's services?
   - Support with personal care
   - Take family member for social outings/activities in community
   - Assist with behaviour teaching strategies
   - Assist with life skills to help with daily living activities (completing paperwork, online or telephone tasks, problem solving)

4. There is often a waiting period to access ABI services. What would be the most important ways to make the wait more acceptable/bearable?
    - Centralized ABI grief counselling to manage loss
    - Check-in from a support person to ask for updates, answer questions
    - Informal group sessions about ABI
    - Access to a real person you can call to discuss options to bridge gaps while waiting
    - Receive regular status reports (more frequently than just once a year)
    - Concrete access to emergency services when there is a crisis and respite after
5. Sometimes a caregiver can feel somewhat disconnected from their community (e.g., not feeling their life situation is understood, having different ways of living ones family life, possible stigma toward ABI). The most important ways that this feeling can be alleviated are:
    - ABI education in community to increase awareness (similar to Mental Health Campaign)
    - Access to group therapy/centralized support provided by hospital and or ABI associations (e.g., website with "ask an expert" and monthly newsletter)
    - Ongoing consultation with families during treatment
    - Brain Injury Awareness week should encourage more community engagement and more ways to disseminate information
6. What do you feel are the most important non-family type of activities (e.g., schooling, adapted work, volunteering, social outings, socializing etc.) your family member with an ABI would find meaningful?
    - Schooling
    - Meaningful activities (creative/vocational tasks/volunteer work)
    - Social outings

Appendix 5

Sample Organizational Chart



Appendix 6

INESS-ONF Community Based Rehabilitation Recommendations

Guideline Statement	Current State	Future State Recommendations
D 2.1		
Individuals with ongoing disability after traumatic brain injury should have timely access to specialized outpatient or community-based rehabilitation to facilitate continued progress and successful community reintegration (adapted from NZGG 2007, 6.6, p. 116).	• Delayed access to limited services • Multiple waitlists	• Evidence focussed hub and spoke model • Case management for complex patients • Enhanced telerehab capacity
D 2.2		
A peer supported relationship model of intervention within a community-based program should be available to individuals with traumatic brain injury in order to promote social integration, coping and psychological functioning (INESSS-ONF, 2015). REFERENCE: ERABI 2014, Module 13, p.17	• Lack of supportive housing • Limited continuum of services to support social integration	• Model of care that supports transitions to the right setting • Enhanced systems level navigation
D3.1—NEW		
All individuals with traumatic brain injury should be assessed for their level of independence in activities of daily living (ADLs) and instrumental activities of daily living (IADLs) (INESSS-ONF, 2015).	• Lack of access to full spectrum of services	• Clinical direction of sole provider
D3.3		
An individualized life skills training protocol should be developed for each person with traumatic brain injury, to assist them in dealing effectively with the demands and challenges of everyday life. Depending on the needs of the person and his/her impairment profile, life skills training may focus on social skills, activities of daily living/ instrumental activities of daily living (ADLs/IADLs), interpersonal skills, job skills, problem-	• Limited transition of current individuals receiving service • Case management available for individuals with 3rd party insurance being missed	• Evidence based development of community rehabilitation to provide the right services, closer to home • Focus on assessment, intervention and transition

Guideline Statement	Current State	Future State Recommendations
solving skills, decision-making skills, self-advocacy skills, behavioural self-regulation skills, etc (adapted from AOTA 2009, p. 83).		• Consultative support to other providers
D 4.2		
Individuals with traumatic brain injury with difficulty undertaking leisure/meaningful activities of their choice should be offered a goal directed community-based program aimed at increasing participation in leisure/ meaningful and social activities (adapted from ABIKUS 2007, G97, p. 32).	• Limited capacity available	• Expected enhanced capacity through transitional model
E 1.1		
Rehabilitation programs for individuals with traumatic brain injury should be developed in collaboration with caregivers to ensure carryover into the community (adapted from ABIKUS 2007, G98, p. 33).	• Feedback sought on services by single providers	• Creation of enhanced continuum of services with systematic input from clients and caregivers
E 1.3—NEW		
Family and caregivers should be provided with access to ongoing support. Supportive groups and therapies e.g. associations/peer support/mentoring, mindfulness based cognitive therapy, yoga, art, pet or music therapy, etc. should be considered (INESSS-ONF, 2015).	• Fragmented support opportunities.	• Consultative support and enhanced case management

Current ALC Issues

In the Champlain LHIN, TOH has had two individuals with ABI and high needs living in the hospital > 2000 ALC days at a cost of > $945,000 annually. This is a conservative estimate of cost, as it does not include the cost of staff replacement due to injury, the cost of limiting access to service for other inpatients, or the cost to these individuals and their families whose quality of life is significantly reduced. Similar occurrences are happening in community hospitals throughout the Champlain LHIN (e.g., Renfrew Victoria Hospital).

For those who cannot live in the community and do not have high cognitive and/or behavioural needs, the option is a Long Term Care Home (LTCH) which is inappropriate for most ABI clients The ABI Systems Navigator in the Champlain LHIN estimated that there are >100 individuals with ABI in various LTCH facilities in Champlain. The vast majority of facilities do not have trained staff to provide ABI specific care that would improve function and independence and ultimately decrease resource intensity. It should be noted that LTCH facilities often decline admission when there are significant cognitive and/or behavioural challenges as a result of the injury or due to mental health and/or addictions issues. In order to manage challenging behaviours, medication is often used which limits rehabilitation potential to improve independent functioning as well as reducing quality of life.

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